Testimony Regarding Illinois Nursing Homes & People with Severe Mental Illness

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Illinois is in a nearly unique position with regard to its preference for inappropriate, unnecessary, and expensive institutional care for people with severe mental illnesses.

- Illinois is a leader in the use of nursing homes (including Institutions for Mental Diseases or "IMD"' nursing homes) for people with severe mental illness. More than 15,000 of the 125,000 people nationally who are in nursing homes simply due to mental illnesses are Illinois citizens. This is particularly tragic since we have increased spending for intermediate care for people with severe mental illnesses in the past five years and cut the base funding for community alternatives to intermediate care in that same period.
- Illinois is also a national leader in spending on institutional care. In Illinois, 59% of the resources for people with severe mental illness are spent on institutional care and only 41% on community care. Of all available resources, 31% is spent on IMDs alone which serve 1% of the population. In spite of recent efforts to rebalance the system Illinois is still, perhaps, the most imbalanced system of care in the nation.
- Finally, Illinois is a leader in federal lawsuits over institutional care. Illinois has two active Olmstead lawsuits in federal court related to people with severe mental illness in and nursing homes and IMDs as well as a third case involving people with developmental disabilities.

Illinois' policy on the use of intermediate care appears to be outside of national and legal standards for appropriate care for individuals with severe mental illnesses. While I do not believe that there are lots of "good guys and bad guys" in this situation, I am convinced that the thousands of individuals who are inappropriately placed in nursing homes and the taxpayers of Illinois who cover the cost of these placements deserve better. There are at least five reasons to re-examine our use of nursing homes for people with severe mental illnesses.

- **We are placing seniors in nursing homes at risk.** The mixing of young people with seniors in nursing homes creates opportunities for violence towards seniors. The issue is not simply one of people with mental illness mixed with seniors. It is the inherent problems involved in placing large numbers of people under the age of 55 who do not have real medical conditions in institutional settings with vulnerable seniors. It is simply an invitation to difficulties. These difficulties are compounded by the inadequate behavioral health services in most nursing homes, poor screening practices, and a lack of services to individuals who present higher than average risk.
- **We are spending money defending federal lawsuit over the use of institutional care during a time of fiscal crisis and not living up to the spirit or the letter of federal law.** When one reviews the outcome of an Olmstead case decided this fall in New York, it seems likely that Illinois will ultimately lose its Olmstead lawsuits related to people with severe mental illness. We should stop spending tax dollars defending and start developing a settlement of which we can be proud.
- **We are opening too many institutional beds compared to community services.** For example, the number of IMD beds in Illinois increased from 5,400 in 2002 to 6,100 in 2006 and the cost of each bed has climbed by the year. Contrast that to community care. Adjusted for inflation, the

funding base of community funding has shrunk 15-20% over the past five years at the same time that new billing and compliance related administrative costs have skyrocketed. In short, we are shrinking community care and expanding intermediate care for people with severe mental illness. That is simply bad public policy and it is unique to Illinois.

- **We are spending scarce taxpayer money during a time of fiscal crisis on expensive and unnecessary institutional care**. Each nursing home bed costs $35,000 to $40,000 per year. This is significantly more expensive than community care. The IMDs are also far more expensive than community alternatives and cannot collect Medicaid for their work because the Federal Government refuses to sanction and support long term, segregated institutional care for people simply because they have a mental illness. The excessive use intermediate care costs Illinois taxpayers at least $100 million a year in lost Medicaid revenue and excessive costs. It is also worth noting these homes, generally privately owned, can be quite profitable. Some sectors of intermediate care for people with severe mental illness generated an aggregate profit of 22.4% for the period of 2002-2003. That makes them quite different from non-profit community providers which typically achieve margins of 1-2%.
- **We are reducing the quality of life for thousands of Illinois citizens with severe mental illness and reducing their chances for real recovery and a good life** by relegating them to intermediate care. Few people would want to live in an institutional setting if community alternatives are available. We all know that nursing homes, while necessary for some people at some points in their lives, are not a place that we would choose to live. And it would certainly not be our choice if we were in our 40's or 30's or 20's or even younger. In Illinois we routinely place young people in nursing homes simple because they have a mental illness. Thresholds has even taken teenagers out of intermediate care facilities. These are young people who have no underlying medical condition that requires nursing care and for whom community alternatives work better. They have mental illnesses and are in need of community support and recovery services, not in need of being locked away.

In short, it is a bad public policy that spends far more than necessary to serve people with severe mental illnesses. It is a cruel public policy that relegates people with severe mental illness to marginal lives in institutions with limited opportunity. It is a dangerous public policy that all too often places vulnerable seniors at risk. And it is an astonishing public policy to defend these violations of federal law in court. But this is precisely the situation that we face in Illinois. **Illinois citizens who depend on public mental health services as well as their families, friends, and neighbors deserve better. And Illinois taxpayers who fund these services deserve more responsible fiscal management.**

I refuse to point fingers or take cheap shots at any of the parties to this situation. I am sure that when the policies were put into place to create this dependence on intermediate care, the policies made sense. This situation has been years in the making and there are no villains or heroes in the story. That being said, all of us as citizens of Illinois bear some responsibility for the situation and for addressing it. Those of us in this room have particular responsibility for finding a policy solution that serves the citizens of Illinois better than the status quo does. And I believe that we can.

The solution to this situation is straightforward. It does not take more money. If fact it saves money. It does not require developing exotic community services. Eighty-five percent or more of the residents of intermediate care who are there simply due to mental illness could be served in the types of community services that already exist if only Illinois were willing to fund more of them. Thresholds now routinely moves people with severe mental illnesses out of intermediate care, and we could help many more by shifting funding from intermediate care to community care and increasing Illinois' commitment to assertively leading the development and management of community care alternatives.

We need to get the large majority of people who do not have significant medical needs out of intermediate care facilities and reduce intermediate care capacity for people with severe mental illness. And we need to develop community alternatives to intermediate care. I do not believe that many people would dispute that we have too many institutional beds, too few community beds, and a need to balance the service system. The conversation should be one of "how quickly can we accomplish this" rather than can we or should we. I suggest the following four points as a framework for the conversation.

1. **Consider a Joint Settlement of the Two Olmstead Cases Involving Plaintiff with Mental Illness**: The two Olmstead cases now in federal court have similar requirements for settlement. Both cases require reduced intermediate care capacity and both require significant increases in community capacity to serve people with mental illnesses. The settlement in each case should include attention to the other case in order to avoid unanticipated transfer of individuals between the IMDs and nursing homes. In addition, coordinated and focused activity to develop community capacity will be required and should be done as a single project. While it would be a mistake to hold up one case waiting for the other, the state should consider an assertive and rapid settlement offer for both cases.
2. **Eliminate Most Uses of Regular Nursing Homes for People with Mental Illnesses:** Illinois should take this opportunity to settle the Olmstead nursing home lawsuit and establish clear and firm regulations that prevents anyone under the age of 55 who does not have a specific medical diagnosis that requires significant skilled nursing support from living in a nursing home. In addition, Illinois should limit by regulation the total number of people who can be in any nursing home as a result of mental illness to less than 5% of the daily census of the home. At least 85% of the savings from reduced use of intermediate care should be transferred to the development and operation of community services. These steps to reduce population mixing and risk of violence towards seniors could be phased in over a period of five years. The best IMDs could be strategically engaged in this process to provide placement opportunities for the small percentage of nursing home residents who cannot be easily relocated to the community.
3. **Reduce IMD Capacity By At Least 60-80% in The Next Five Years**: Illinois should take this opportunity to settle the IMD Olmstead lawsuit. IMD capacity should be reduced by an average of approximately 600-800 beds a year for the next five years and transfer at least 80% of the savings from associated general revenue funding and potential Medicaid match to developing community services. The speed of the capacity reduction should be informed

by the efforts to reduce the use of nursing homes for people with severe mental illnesses. At the end of five years, we will still have approximately 1000 to 2000 IMD beds available for people with unique needs for whom community capacity is yet to be developed. It should be noted that some IMDs offer better services than others. The state should preserve the best of the IMDs during this transition. At the end of this initial phase of the process, Illinois and the court can evaluate the ability of the state to further reduce the number.

4. **Build Stronger Community Services Infrastructure:** Eliminating most intermediate care for people with severe mental illnesses in Illinois and developing good community alternatives is a substantial project involving the creation of capacity for at least 10-12,000 individuals over the next five years. This project can be successfully completed if Illinois is commits to its success. It will require an investment in infrastructure at the Division of Mental Health and in provider organizations but it will save money over the coming few years. A small working group endorsed by the Governor, led by the Division of Mental Health, supported by the Legislature, and overseen by the court be assembled to lead this project. Outside consultation should be engaged assist in the planning and execution of the project and to provide a national perspective on strategies for a successful project.

For far too long, Illinois has pursued a policy of intuitional care that is overdue for change. The current policy is not in the interest of its taxpayers or its citizens with severe mental illnesses. We need to reverse that course. We have the money and the programmatic leadership to create exceptional community services if we have the courage to act. It is the right fiscal thing to do. It is the right clinical thing to do. It is our legal obligation. It is the right public policy to implement. And it is the right thing to do for our friends, neighbors, and loved ones who have severe mental illnesses. Let us make a real commitment to their recovery and fund community mental health services instead of institutional care. Our citizens deserve better public policy in this area.

Testimony of Equip for Equality Before
Senate Human Services and Public Health Committees
Nursing Home Resident Safety Hearing

Chicago, Illinois
November 5, 2009

Equip for Equality is an independent not-for-profit organization designated by the Governor in 1985 to administer the federal Protection and Advocacy System for people in Illinois with physical or mental disabilities. Equip for Equality's mission is to advance the civil and human rights of people with disabilities and is accomplished through self-advocacy training and technical assistance, legal services, and public policy initiatives. In its capacity as an independent watchdog, Equip for Equality also conducts unannounced on-site monitoring visits to programs and facilities, including nursing homes, across the state and engages in systemic investigations to address abuse and neglect of people with disabilities. We appreciate being given an opportunity to provide testimony before the Committees.

Mental illness cuts across all races, ethnic groups, socio-economic groups, and age groups. It is more common than cancer, diabetes or heart disease. In Illinois, 2.6 to 3.9 million people (20-30% of the population) will be affected by mental illness in any given year. Without treatment and support, the consequences of mental illness to individuals and to the State can be devastating. Frequently, it results in unnecessary hospitalization, unemployment, substance abuse, homelessness, inappropriate incarceration, stigma, and far too often in tragic consequences such as suicide.

In spite of the prevalence of mental illness, Illinois has failed to develop an adequate community based mental health system capable of providing easily accessible and individualized supports and services which would allow people to recover while living their lives in their own homes and communities. Instead, Illinois' grossly under funded community mental health system has meant that services are simply not available to thousands of people in need resulting far too often in people being warehoused in nursing homes and other institutions.

While we appreciate the call to action that has resulted from the articles in the Chicago Tribune, we are deeply troubled by the stigmatizing effect of the articles and the characterization of people with mental illness as dangerous and in need of segregation because of a perceived propensity to commit crimes. This stereotypical notion, while prevalent, has been repeatedly and thoroughly refuted. Studies show that more than one quarter of persons with severe mental illness has been a victim of a violent crime, a rate

more than 11 times higher than the general population.[1] Among persons with severe mental illness, violent victimization is far more prevalent (more than 25% in 2005) than perpetration of violence (4% -13%). Thus, the reality is the inverse of common belief: people with serious mental illness are far more likely to be the victims of violence than its initiators. Blaming the victims is the real danger here because it rationalizes neglect and maltreatment of people with mental illness. Far from being the aggressors, people in nursing homes are much more likely to suffer injury at the hands of staff from poor care, neglect and abuse.[2]

At present, long-term care for people with mental illness in Illinois is primarily provided in institutional settings such as state-operated mental health centers, nursing homes, and Institutions for Mental Diseases (IMDs). The State spends a disproportionate amount of its mental health budget on providing services in segregated settings rather than in the community. The current service system is contrary to the community integration mandate of the Americans with Disabilities Act (ADA) and the Supreme Court's *Olmstead* decision. In addition, it is designed to intervene only *after* individuals have reached an acute stage of illness. Neither the individual's quality of life nor the State's economic interests are promoted by such a system.

In Illinois, more than 5,500 individuals with mental illness are housed in large nursing homes referred to as IMDs. These facilities, which are privately owned, are funded 100% by the State. Federal law prohibits the State from recapturing any federal funds for the amount spent on IMDs. If Illinois instead spent these funds on community mental health services, it would be able to recoup a significant portion of the cost in federal Medicaid dollars.

In spite of a 2003 national call to transform America's mental health care system to one in which children and adults with serious mental illnesses live, work, learn and participate fully in their communities, individuals in IMDs, and other nursing homes in Illinois still do not receive sufficient or, in some cases any, services, training or assistance to facilitate recovery and build resiliency to withstand life's challenges as full participants in community living.[3]

More importantly, this is by no means a new problem. In 1986, a report authored by the Institute of Medicine on improving the quality of care in nursing homes suggested that people with severe mental illness who were deinstitutionalized from state mental health hospitals were discharged to nursing homes that could not provide the specialized

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[1] Linda A. Teplin, et al., *Crime Victimization in Adults with Severe Mental Illness: Comparison with the National Crime Victimization Survey*, 62 Archives of General Psychiatry 914 (2005) ("People associate mental illness with violence. Crime and mental illness are linked, but not in the way people think. People with severe mental illness are terribly vulnerable to victimization.").

[2] *Abuse in Nursing Homes,* National Center on Elder Abuse Newsletter (National Center on Elder Abuse, Washington, D.C.), May 2002, at 10.

[3] The President's New Freedom Commission on Mental Health, *Achieving the Promise: Transforming Mental Health Care in America* (2003), *available at* http://www.mentalhealthcommission.gov/reports/FinalReport/downloads/FinalReport.pdf

services they needed.[4] The report also raised concerns that even the former state hospital patients who needed a nursing level of care were not receiving the minimally necessary level of mental health treatment in nursing homes.[5] The federal Omnibus Budget Reconciliation Act of 1987 was a major policy reform directly addressing the lack of appropriate mental health services in nursing homes. Despite regulations requiring mandated screening for mental illness, studies have reported low rates of implementation of recommended mental health services. A study conducted in 1997 found that among nursing home residents with an identified psychiatric diagnosis, only 36% received any mental health visits that year. More recent data indicate that approximately one-fifth of all nursing homes receive a deficiency citation each year for problems with or a lack of mental health care as part of the federal survey and certification process. As recently as August of this year, the Government Accountability Office published a report stating that Illinois had the second highest number of poorly performing nursing homes in the country.[6]

Equip for Equality's efforts to address the lack of services and the dehumanizing conditions which result from warehousing people with disabilities in institutions has been longstanding. Equip for Equality's onsite observations and investigations of the quality of mental health services provided by nursing homes confirm the findings identified in the studies cited. Not only do nursing homes routinely fail to provide meaningful mental health services, often there are simply none. Our investigation of programs that nursing homes send people to, along with the investigations of other investigatory agencies, documented that since 2002, millions of taxpayer dollars have been wasted in payment of services allegedly provided by doctors to address the mental health needs of those involved in the programs. In spite of the amount of public funds that have been spent, the services and programs did not resemble any form of actual mental health services. Rather, as one program administrator best described, the programming offered was "abysmal" adding that "programming" at many of the sites consisted of nothing more than smoke filled rooms, television groups, and poorly trained staff.[7]

The key to improving the State's mental health system is to increase funding and support of quality community mental health services that are readily available and easily accessible. While currently resources are few, there are some community programs that have been successful in maintaining people with schizophrenia, bipolar affective disorder, and other serious mental illnesses in the community. With sufficient resources, the best community programs could expand these activities, which, in turn, would

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[4] Institute of Medicine, *Improving the Quality of Care in Nursing Homes* (1986).

[5] A GAO report from 1982 documented the same problem. "Often . . . mental conditions remain undiagnosed because nursing homes are not equipped and have little incentive to provide mental health diagnosis or treatment. Left undiagnosed and untreated, mentally ill nursing home residents have limited prospects for improvement." U.S. Gen. Accounting Office, *The Elderly Remain in Need of Mental Health Services* 5 (1982).

[6] U.S. Government Accountability Office, *Nursing Homes: CMS's Special Focus Facility Methodology Should Better Target the Most Poorly Performing Nursing Homes, Which Tended to Be Chain Affiliated and For-Profit* 15 (2009).

[7] Equip for Equality, Ensuring the Safety of Children and Adults with Disabilities: Filling the Gaps in Illinois' System that Investigates Allegations of Abuse and Neglect (2008).

alleviate many of the problems associated with mental illness. Although at present such resources are scarce, there are things that can be done in the community for individuals with mental illness, such as crisis intervention teams, intensive outreach, and peer programs. These measures seek to engage individuals with mental illness, including homeless people with mental illness, who are not connected to any services and to develop a relationship of trust with them, so they choose to become involved in treatment. Individuals who seek treatment voluntarily are far more likely to benefit from the treatment, thereby improving their long-term prognoses.

As currently structured, the mental health system in Illinois does not meet the needs of the individuals it is intended to serve. To create and sustain an effective, cost-efficient and person-centered long-term care system, it is necessary that the State inform its service plan and strategies through the involvement of people with mental illness to provide the State with their perspectives on the services they need and desire. In addition, it is necessary that the State: 1) substantially decrease its reliance upon institutional care for people with mental illness; 2) substantially increase its funding and support of community mental health services; 3) take a proactive rather than reactive approach to mental health care; 4) provide a variety of individualized services that will meet the needs and desires of people with mental illness, including adequate acute care as needed, to allow for full participation in community living; 5) provide flexible and individualized pharmaceutical care; and 6) maximize its ability to capture federal Medicaid dollars for the mental health services it provides.

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Testimony before a joint hearing of the Illinois Senate Public Health Committee and Human Services Committees

Room 16-503 of the Thompson Center, 100 West Randolph Street,

November 5, 2009

Thank you for the opportunity to testify today. It is an honor. I know that is the standard thing to say but for someone who indentifies as mentally ill and at risk of homelessness it is particularly true.

As mentioned, my name is Fred Friedman. Before I begin to testify about my experience in a nursing home and my suggestions for improving the system let me tell you a little about myself, my credentials if you will. I am very sick and very poor. Those facts are, of course, related. I suffer from a severe, persistent, chronic mental illness. Like most people with a severe mental illness, I also have physical problems. We die on average 25 years sooner than people without mental illness. In my case, I have Ankylosing spondylitis which means that my bones are fusing together. This is why I am so stiff. I also have severe sleep apnea, which means even when I sleep I do not get the rest I need. It is one reason, that I have these deep bags under my eyes that make me look kind of dangerous.

About ten years ago, when my mental illness symptoms were particularly acute, I lost nearly everything that was important to me. I lost my wife of 24 years, my profession of 20 years and most of my processions, including my home of ten years. I spent a year and half in my living room, (as my ex-wife says" lying in my own feces") a year and half in Clayton Residential Home, a nursing home, and ten months in a homeless shelter. I have been living on my own for about eight years.

On the day my divorce became final; my ex-wife put me in Clayton. I later learned it is an IMD, an institution for of mental disease, a kind of nursing home. My testimony today is about my experience there. In some ways, the testimony is limited. My direct knowledge of nursing homes is limited to one nursing home, and perhaps dated. On the other hand, it is based on firsthand experience and is disinterested. Not uninterested but disinterested. Whatever you decide about nursing homes will not directly affect me. I also am the co-founder of Next Steps a community of mentally ill and homeless people. I have spoken to dozens if not hundreds of current and former residents of IMDs and nursing homes. While I am speaking of my own experience, my conversations with my peers suggest that the situation has not changed for the better since I was personally in a nursing home.

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I have heard that Clayton is the best nursing home in the state for people with mental illness… the best IMD. I do not know if this is true but I do know that my wife thought so before she put me in it. Bear that in mind when I talk about my experience. This is not a particularly bad nursing home this maybe the best.

Before I could live in Clayton, I had to sign some contracts. I am a lawyer by training and do not fully understand how I could be competent to sign and be bound by contract yet so sick that I needed to be in an IMD. It was irrelevant because I did not read the contract. My ex-wife said latter that was the first time she ever saw me sign a contract without reading it.

I saw a psychiatrist. He prescribed depakote. I learned later it is used to treat Manic-depression. It only treats the manic symptoms. To my knowledge I have never had a manic episode. Except for this instance, I have never been diagnosed with manic depression. I had just spent the last year and half lying in bed. He gives me a med that prevents me from becoming manic. One of the common side effects of Depakote is weight gain.

I saw a case worker. She had me sign some more papers. She had folded them over so I could not read what I was signing. I found out latter it was my "goals." She decided my goal was to lose weight. I did not have a home, a job, or a relationship but the only problem I should work on was losing a few, or not so few, extra pounds. This is particularly ironic because they fed me and I had no choice in what I ate or the potions of what I ate. Moreover depakote is contraindicated in overweight patients because it might cause weight gain. Id.

There was more than "medication treatment" and "case management." There were also rehabilitation groups.

They had an "art therapy" group. It consisted of filling in coloring books.

They had a "public events" group. It consisted of taking turns reading the Sun-Times out loud.

Then, as now, the personal needs allowance for a person in nursing homes was $30 a month. I spent $12 of that going to see my therapist at Jewish family services once a week. Other than that, and the medication treatment, I have previously talked about. I received no therapy at the nursing home.

From time to time, I was tested. Among other things, they checked to make sure I could count change and read a clock.

My therapist from Jewish Family Services found me a place at live: Singer Center. It was run by the ARK a Jewish social service agency. When I was accepted I told the folks at Clayton that I was going to leave, I was told that the contract I signed

said I could not leave without 30 days notice. My therapist convinced the ARK to keep my bed open for 30 days.

On the week I was set to go to the ARK, I discovered that my father and sister were deathly ill. I received permission to go to Florida to see them. I had two weeks of medication. My father died the day after I got to Florida. My sister was in a coma. I buried my father and waited for my sister to get better. It took four and half weeks. When she got out of the hospital, I made arrangements to go back to Clayton because my bed at Singer was gone.

When I returned to Clayton I found that my door was plugged and I was locked out. I thought this was a violation of the forcible entry and detainer act. As I was thinking about it, someone came up and said that I was going to the hospital. When I asked why, I was told that I was without my meds for a few weeks. I said I did not think this was grounds for involuntary commitment. I asked to look at the order for commitment and the only symptom listed was being without meds for a few weeks. They assured me it was. The fact that I had traveled to, and from, Florida, buried my father, and lived by myself for a few weeks did not indicate that I could live in the community. It indicated that I needed to be hospitalized. The ambulance came; the attendants strapped me in a gurney and took me to Riveredge hospital.

Since, the place I lived at was not available to me, I had no other place to live, and I was told the other option was Read State Hospital, a place I really would not like, I signed a voluntary admission. I spent 4 weeks in the hospital and then.... I was cured and told I had to leave. I am sure it is only happenstance that Medicaid only pays for 4 weeks of hospitalization.

I went back to Clayton. Eventually my therapist from JFS talked the ARK into taking me again. I gave my notice. I met with the head of clinical care for the first, and only, time. He asked why I wanted to leave. I said I was not getting treatment.

He said "You could have had treatment, all you had to do was ask. You have to take some responsibility for your care." Apparently coming to live at Clayton was not taking responsibility. Sort of like going to the emergency room with a broken leg but not crawling to the orthopedic department is not taking responsibility.

He told me that "You should not leave because you are not sure that it would work out". And that I do not know why you want to leave. I see you in the TV room reading all the time. Why is that not enough?" A middle aged lawyer spends all day in the TV room reading and he sees nothing wrong with that picture.

On the day, I was to leave; I was told that I could not because I had not given notice. I said "that I had, didn't she remember." She said that she did but it was outside

the office and so did not count. I said I was leaving anyway. She made me sign a form saying I was leaving against medical advice. And I left.

What is my solution to the problem?". The difficulty for me with that is for any problem there is a solution that is simple, clear, and wrong. The second difficulty is that I am not sure what problem you want to fix. In my opinion the problem is that people who could recover are warehoused. The reason for this is simple, the present system gives little or no incentive to make people better. Clayton gets paid only as long as the resident remains and most of the cost are fixed. If I got better they would have to fill the bed with someone else, or lose over a hundred dollars a day. I was warehoused and got out only because I was very lucky. Please help my brothers and sisters who not as lucky.

There is a no brainer partial solution: settle Williams v Quinn which is presently pending in federal Court. It is a class action alleging that the placement of so many persons with mental illnesses in IMD nursing homes violates the Americans with Disabilities Act (ADA) as interpreted by the United States Supreme Court in *Olmstead v. LC.* Recently a Federal court in New York found that New York's placement of persons with mental illnesses in board and care facilities violated the ADA suggesting that Illinois' policies are likely to be found illegal as well.

There are Band-Aids.

1. Raise the amount of money people in nursing homes receive as personal need allowance. It has been $30 a month for a long time, at least 10 years. I have testified about this and both houses passed a bill which would raise the allowance but because a dispute between the houses it did not make it to the governor's desk.
2. Raise the amount people in nursing homes can earn and keep.

Next Steps proposes a new mental health initiative, "**Recovery and Empowerment based Mental Health** " based on the principles of the mental health recovery movement: self-determination, empowerment, low cost, and whole health: These policies would facilitate recovery and community inclusion, while reducing costs. They help mental health consumers take an active role in making the transition from tax spenders to tax payers at a time when our economy is in trouble. Recovery, peer support, and self-help decrease mental health costs and social security payments, and improve the overall health of our communities. Many of these new policies center on the employment of mental health peers. A mental health peer is a person who has experienced their own recovery from mental illness and has learned to use what they have learned to facilitate recovery by other mental health consumers. Our policy proposals are:

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1. **Consumer-driven system:** Illinois should facilitate a shift to a Recovery and Empowerment based Mental Health system through ensuring that the voice of mental health consumer/survivors and all persons with disabilities are heard in an ongoing, meaningful manner at all levels of care from treatment planning to planning and policy formation at the agencies affecting our recovery: This can be carried out by sustainable funding of consumer-run statewide advocacy organizations, and technical assistance centers to assist in their development, coordination, education, and integrity, as well as representation by consumer representation by these advocacy groups on advisory boards to each of the agencies that effect their lives. This recommendation is in line with the New Freedom Commission's Report.

2. **Recovery-based alternatives to institutionalization:** there need to be in every community a combination of peer-run: crisis respite centers, warm lines (telephone support), in home supports, and recovery-social networking centers. These alternatives reduce costly psychiatric hospitalization, jail use, and nursing home placement.

3. **Self-directed community-based care:** We promote the use of Personal Care Assistants for mental health (as is being carried out in Oregon), person-directed recovery planning (as is done in Western New York State), and self-determined budgets and personal financial management planning (Florida Self-determination Program). CMS has shown an interest in these reforms at a federal level, but the state Illinois Medicaid directors need educating
4. **Expanded employment and education of persons with mental health diagnoses:** pay for Supported employment and supported education

5. **Expansion of safe, affordable, community-based homes:** Research shows that individuals with disabilities can and do live successfully in homes of their own in the community. The production of affordable, permanent homes is an essential component of a system of care that has a focus on the individual's recovery and gaining a meaningful role in the community. In particular, it is important to develop home choices that offer individuals the same opportunities that are available to anyone in the community. These choices need to be lease-based and have tenancy, and tenant rights as the core, rather than service delivery based housing, which most often is available in the form of group homes with mandatory services attached. Efforts need to be made to creatively pool a variety of funding streams across administrations in order to fully develop a new homes production strategy that is linked to a Landlord/tenant or ownership model, rather than a patient/provider service delivery model. Also Housing First type model

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programs, which appeal to persons who are homeless as they are free of many of the requirements of usual programs.

6. **Person-centered Whole Healthcare reform:** psychosocial elements are as important to health as the medical aspects so we suggest that health care reform reframe the concept of medical necessity to encompass psychosociomedical as a whole. The concepts of Person Centered Planning and Quality Improvement are inextricably linked, in the IOM Quality Chasm series report on mental health and substance use disorders. Evidence-based practices by definition must be person-centered and directed, e.g. self-directed care (HHS and other agencies have pilot data on the outcomes of this and other aspects of recovery). It will be necessary to think about how some of the best aspects of the public healthcare and mental healthcare systems will fit better into the private sector, which has benefited from cost-shifting of care for more seriously ill and disabled individuals from the private sector to the public sector.

I would be pleased to answer any questions.

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